What is Rett Syndrome?

Rett syndrome is a developmental disorder that affects the brain and nervous system. It occurs mostly in girls of all racial and ethnic backgrounds. After a period of normal development, the condition causes serious developmental problems and difficulty with movement. Rett syndrome occurs in approximately 1 in 10,000 to 15,000 females. It is very rare in males but can occur.

How may Rett syndrome affect my child?

Learning: Affected girls develop normally until about 6 to 18 months of age. At that time, language and motor skills are quickly lost. Speech and control of hand movements are most often affected. After the time period when skills are lost, the level of development may remain stable. Older children may have slow improvement in some areas.

Behavior: Many girls with Rett syndrome have panic-like attacks and inconsolable crying. Teeth-grinding is a common trait. Some other behaviors may be similar to those found in children with autism.

Physical: Body movement is affected over time. Purposeful hand movements are replaced with repeated wringing, washing, or clapping gestures. Most girls with Rett syndrome are small for their age. Foot and hand deformities and curvature of the spine (scoliosis) are common. Broken bones tend to occur more often than in other children.

Medical: Smaller head size (microcephaly) develops in early childhood. Feeding and digestive problems are common, including constipation. Abnormal breathing patterns and seizures (epilepsy) may also occur.

How does Rett syndrome occur?

Rett syndrome is caused by a change in a gene on the "X" chromosome. The genetic cause can be found in most children with Rett syndrome. The child is usually the first and only family member affected. In rare instances, the condition can recur in sisters or brothers. Genetic counseling is recommended for parents to learn about the genetic cause of Rett syndrome in their family, and possible risks for other children.

How is Rett syndrome treated?

Rett syndrome cannot be cured, but some symptoms can be treated. Infants and toddlers (birth to 3 years) should be connected with *Early On*® Michigan as soon as possible. If there are concerns about learning, speech, or behavior in a child over 3 years of age, a referral for special education services should be made. A speech therapist can help find the best way for a child with Rett syndrome to communicate. Occupational and physical therapy help with movement and mobility. Other therapies or treatments may be needed for problems as they arise. Children with Rett syndrome and their families benefit from having a primary care physician who helps to coordinate their care with medical specialists and other community-based services.

For more information, call Michigan's Genetics & Birth Defects Program toll-free at 1-866-852-1247 or e-mail Genetics@michigan.gov

Michigan Resources & Support

Children's Special Health Care Services
Family Phone Line
Toll-free: 1-800-359-3722
E-mail: ppp@michigan.gov
www.michigan.gov/cshcs

***Early On*® Michigan**
Toll-free: 1-800-EARLY ON
www.1800earlyon.org

Michigan Birth Defects Program
Nurse Follow-up Coordinator
Toll-free: 1-866-852-1247
E-mail: BDRfollowup@michigan.gov

Michigan Genetics Connection
www.migeneticsconnection.org

National Resources & Support

International Rett Syndrome Association
Toll-free: 1-800-818-7388
www.rettsyndrome.org
Includes RettNet web forum

Rett Syndrome Research Foundation
Phone: 513-874-3020
www.rsrf.org

Family Village
www.familyvillage.wisc.edu

GeneReviews
www.geneclinics.org/profiles/rett

Genetic and Rare Diseases Information Center
Toll-free: 1-888-205-2311
E-mail GARDinfo@nih.gov

Genetics Home Reference
www.ghr.nlm.nih.gov/condition=rettsyndrome

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